

## Challenges Associated with Partnering with Sudanese Refugee Women in Addressing Their Health Issues

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### **Abstract**

Civil war in Sudan has displaced refugees all over the globe. A community-based collaborative action research project (CBCAR) took place over one year between university researchers and southern Sudanese refugee women. The purpose of the study was to define the process of partnering with Sudanese refugee women to address their health needs. CBCAR requires equal participation from researchers and participants and is divided into six cyclical phases: partnership, dialogue, pattern recognition, dialogue on meaning of pattern, transforming insight to action, and reflecting on evolving pattern. Challenges from this project were examined from the perspectives of the researchers and the participants. The main challenges associated with conducting a CBCAR project between researchers and refugee women included: misunderstandings and differing expectations of research outcomes, language barriers, and cultural differences. Despite the challenges, this project led to increased knowledge for participants and researchers and improved health outcomes for the refugee women. This study demonstrates how CBCAR is a useful method to partner with refugees to address their health needs.

### **Introduction**

At the beginning of 2011, there were 10.4 million refugees of concern in the world (United Nations High Commissioner for Refugees (UNHCR, 2012). Commonly confused with immigrants, who choose to leave, or internally displaced persons, who are displaced within their own countries, a refugee is a person who,

Owing to a well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinions, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country (International Organization for Migration (IOM), 2004).

Refugees are forced to flee their home countries for many reasons, including economic, social, violent, ethnic and religious concerns. They are not safe in their home states, and often unwelcome in surrounding areas, foreshadowing a dim future for the well-being of themselves and their kin.

As a continent, Africa is responsible for large numbers of refugees in different regions. The UNHCR budget for humanitarian programs in Africa in 2010 totaled 1.2 billion US dollars (UNHCR, 2012). However, without funding for these programs, many Africans would be deprived of the most basic needs like food, water, shelter, and also denied health services and education (UNHCR, 2012). Africa faces major challenges with population growth combined with scarcity of resources. For too many Africans, seeking refuge within, or elsewhere abroad, is not optional, but mandatory.

Sudan is an eastern African country that has been plagued with civil war for more than three-fourths of its existence as a country (U.S. State Department, 2012). The two most heightened periods of violence were in 1956-1972 and 1983-2004 (IOM, 2011). It is estimated that 2 million Sudanese lives were lost from the second war and effects from famine (IOM, 2011).

Differences in culture and religion, as well as social, economic and political issues, have divided Sudan since the southern half gained independence from the United Kingdom in 1956 and the northern half gained independence from Egypt in 1956. Arab-led Khartoum government failed to keep promises to southerners to create a federal system, which led to a rebellion by southern army officers (U.S. State Department, 2012). Ongoing conflict can be largely attributed to effort of northern government to unify the country along the lines of Arabism and Islam, despite the opposition of the predominantly Christian southerners (U.S. State Department, 2012). Over 90% of the population of South Sudan identifies themselves as Christian (U.S. State Department, 2012). The Sudanese Christian community is “disproportionately represented in the resettled populations globally” (Schweitzer, et. al., 2006, p. 180).

Providing social peace, religious freedom, and economic opportunities, the United States is a distant, yet common, destination for Sudanese refugees not migrating into neighboring countries. Between the years of 2000 and 2007, the U.S. received an average of 3,108 Sudanese refugees per year, with the highest percentage being in the age range of 25-39 years (IOM, 2011). The Sudan-born population in the U.S. has grown from a census estimated 19,800 in 2000, to about 42,000, according to the American Community Surveys (IOM, 2011). Of these Sudanese immigrants and refugees living in the United States, 36.9% are women (IOM, 2011).

In 2011, the people of South Sudan voted, by overwhelming majority, to secede from the North (U.S. State Department, 2012). Official results were announced on February 7, 2011 (U.S. State Department, 2012). On July 9, 2011, South Sudan declared independence and emerged as a new state.

### **Review of Literature**

Research has already examined the experiences of resettled Sudanese refugees. A study of resettled Sudanese refugees in Australia, using five questionnaires through a structured interview process, found that each of the 63 participants had experienced trauma in some form, the most common being separation from family, the murder of a family member or friend, lack of food and water, lack of shelter, torture, and rape, respectively (Schweitzer, Melville, Steel, & Lacherez, 2006). Gender was a significant demographic variable, with women overall experiencing more anxiety and depressive symptoms than men (Schweitzer, et. al., 2006). It was also noted that the most common post-migration problems were “concerns about family not living in Australia, difficulties in employment, and difficulties adjusting to cultural life in Australia” (Schweitzer, et. al., 2006, p. 185). This study illustrates how the traumatic pasts of Sudanese refugees effect their adaptations to new environments.

Pavlish (2012) describes her experiences conducting a CBCAR with East African refugees. She used a former refugee as her interpreter. After receiving approval from community stakeholders, focus groups were conducted to assess and analyze refugee women’s perspectives on their health situations. Pavlish found that the refugee women perceived health as broader than physical concerns. As a result, health programs were planned to address the “social, economic, and political contexts” for the refugee women (Pavlish, 2012, p. 46). The primary challenges that arose from Pavlish’s study included: expanding refugee women’s health agenda, changing social norms, and improving refugee women’s daily lives.

An ethnographic study by Baird & Boyle, (2011) researched the influences to the health and well-being of 10 refugee women from the Dinka tribe of South Sudan who were resettled with their children to the United States. The authors identified three main themes within this research that included liminality: living between two cultures, self-support: standing on our own two legs, and hope for the future.

Liminality, or living between two cultures proved to be a big challenge in the refugee women's transition from Sudan to America (Baird & Boyle, 2011). The Dinka women experienced pressure to keep cultural traditions, such as patriarchy, which are not commonly practiced in the United States (Baird & Boyle, 2011). The most challenging aspect of balancing two cultures for the women was "raising their Dinka children in the 'American way'" (Baird & Boyle, 2011, p. 4). Participants experienced frustration when some of their children, influenced by western culture, began using recreational drugs or having premarital sex. These activities caused concern and conflict for these mothers because they are not aligned with their South Sudanese Christian culture.

The second theme was the women's ability to "stand on their own two feet" in America (Baird & Boyle, 2011, p. 4). This was a big difference from the Sudanese culture in which they were accustomed to the husband being responsible and providing for the wife and children. The women's ability to become financially independent in America gave them a sense of pride as well as "bargaining power" with their husbands (Baird & Boyle, 2011, p. 5). Gaining financial independence aided in the resettlement process for the refugee women.

The final theme recognized in this study was hope for the future. For this community, being relocated to America was a means to "strengthen and secure future generations" (Baird & Boyle, 2011, p. 5). All of the participants expressed a desire to return to Sudan, after gaining education and skills in America, to help those in need. This study found that staying linked to their Dinka community in America and back in their homeland was "vital to the positive adjustment of the refugee women" (Baird & Boyle, 2011, p. 5). Clearly this population did not come to America to put behind their past, but to find hope for the future.

There are many lessons to be learned from doing research with culturally and ethnically diverse groups, especially when working with translators and interpreters. In order to ensure cultural competence with transcultural research, researchers may have to "make adaptations to the usual processes of translation/back-translation when appropriate to the cultural context and the specific situations" (Jones & Boyle, 2011, p. 109). Having trustworthy relationships among the researchers, translators, and interpreters, as well as between the interpreters and participants is imperative for achieving credible study results (Baird, 2011). Strategies for strengthening relationships with translators and interpreters

include, but are not limited to: planning for adequate time and funding for the translation process, describing the qualities of the ideal translator, arranging meetings and interviews with potential translators, and planning time for mutual teaching between the researcher and the translator (Jones & Boyle, 2011).

Sudanese refugees face many challenges when resettling in different countries. Commonly, these challenges center on finding employment in a new country, balancing a different culture with their native Sudanese roots, and providing support and stability to family and friends in Sudan.

### **Purpose**

The purpose of this study was to identify the challenges associated with conducting a community-based collaborative action research project (CBCAR) with Sudanese refugee women to address their health issues. This paper presents part of a larger study that explored the process of partnering with Sudanese refugee women to address their health issues.

## **Methods**

### **Theoretical Framework**

A community-based collaborative action research framework (CBCAR) using qualitative methods was used in this study to capture the challenges the refugee women faced in resettlement. CBCAR is a “relationship-based research process that requires partnered planning, sustained commitment, equitable benefits, and a common desire to address structural health barriers” (Pavlish and Pharris, 2012, p. xii). Using a CBCAR model, researchers can move forward with projects and turn findings into impactful action on a group of individuals or a community. CBCAR requires meaningful relationships, as the participants take equal part in the projects as the researchers. With the goal of social change, CBCAR is unique because the areas of research arise from people within communities or settings where transformation is needed, and research runs its own course instead of following a formula (Pavlish and Pharris, 2012, p. 5).

### **Design and Setting**

This CBCAR study was conducted between January 2011 and December 2011. Five educational seminars and focus groups were held in the Sudanese Community Church in Kansas City, Missouri. These sessions were open to all women in the southern Sudanese

refugee community from different tribes. The sessions were held on Saturdays and included babysitting and lunch. A sixth focus group focused on thematic confirmation and action planning.

Focus groups were used in this study to capture the perspectives of the refugee women. Focus groups are designed to facilitate “carefully planned discussion” in a “permissive and nonthreatening environment” (Owen, 2001, p. 652). This approach to qualitative research is a viable option when working with refugee women because “focus groups do not discriminate against people who cannot read or write” and can provide a “safe environment” for participants to share their thoughts and feelings “without fear of criticism” (Owen, 2001, p. 653).

All focus groups were audio-recorded. Each audio-recorded focus group was transcribed and back-translated. A refugee woman from Sudan who was trained and certified as an interpreter, interpreted the educational sessions and focus groups from English into Dinka and Arabic and back into English again. The educational seminar topics, chosen by the women, were preventative health, sexually transmitted diseases, childhood illnesses, parenting skills, and women’s psychological stress. Students and members of the research team made participant observations, kept extensive field notes, and maintained reflective journals during the entire research process.

### **Student Involvement**

I joined the research team in May 2011 as an undergraduate nursing student as a part of my honor’s project. I was introduced to the Sudanese community, along with the two other students who joined the team, at a Sunday morning church service in July 2011, approximately halfway through the project. In preparation for participation in this study, I made participant observations at the Jewish Vocational Services (JVS), a refugee resettlement agency, and Samuel Rodgers Health Center, a community safety-net clinic that serves refugees. I was particularly interested to learn about the local resources to assist refugees in their transition to America. I attended the last educational seminar on women’s stress and was present for the final focus group concerned with confirmation of themes. I participated in the research process by making observations and taking field notes at the last two sessions. The main focus of my investigation was to identify the challenging aspects of participating in a CBCAR research study with refugee women.

### **Recruitment**

Recruitment methods included advertisement at church service and word of mouth. Women who participated in the South Sudan Women for Change Committee (SWCC) recruited friends and family members to the sessions and arranged transportation.

### **Data Analysis**

Inductive qualitative methods were used to analyze the transcribed focus group data and field notes. Each researcher read and coded the transcripts separately, then met together to discuss and recurring patterns and themes. Data was entered into NVIVO (9.0), a qualitative data software management program, and organized into the six components of the CBCAR framework: partnership, dialogue, pattern recognition, dialogue on meaning of pattern, transforming insight to action, and reflecting on evolving pattern (Pavlish and Pharris, 2012).

## **Results**

A total of twenty Sudanese refugee women between the ages of 21 and 67 participated in the year-long study. The majority of the women spoke Dinka as their primary language and two of the women spoke only Arabic. The average number of sessions attended by a participant was 3.4. Most of the women were mothers and brought their children to the sessions.

### **Partnership**

The first phase of CBCAR is establishing a partnership between researchers and participants. This is achieved by “creating a trusting and meaningful bond between the community and the research team” (Pavlish and Pharris, 2012, p. 17). The partnership for this study started with a meeting in the church with 11 women and the lead researcher to develop a list of health topics. Students and members of the research team were introduced to the community at a church service to establish trust.

### **Dialogue**

The data from this study came from the dialogue of the focus groups. As Pavlish and Pharris (2012) describe how “engag[ing] in authentic dialogue with people very different from ourselves” allows us to “see the world more fully” (p. xix). In the focus groups, participants were able to share how their experiences with resettling to the United States had affected their health needs. During the focus group about women’s stress, the women



shared that their community does not “talk to older women about anything because of respect. [The older women] think [they] are weak if [they] bring [their] problems to them.” Other women expanded on the pressure to keep their Sudanese culture in America, and “if [they] lower [themselves] down to not follow the culture, [they] have low self-esteem.” Dialogue helped researchers to understand the perspectives of the refugee women.

### **Pattern Recognition**

Creating themes is a useful tool in qualitative research as a way to “link the underlying meanings together in categories” (Graneheim & Lundman, 2003, p. 107). When working with transcripts, researchers use coding as a way to analyze data. Graneheim and Lundman (2003) explain how “a code can be assigned to...discreet objects, events and other phenomena” and should be “understood in relation to the context” (p. 107). In this CBCAR study, coding was used to identify themes and patterns from the transcribed dialogue. Multiple themes were found, such as: roles and power, finding common meaning, misunderstandings of the research outcomes, and parenting children in America.

### **Dialogue on Meaning of Pattern**

CBCAR recognizes that both the community and research team should come together to discuss meaning of patterns from the dialogue, and that “findings should be collaboratively and carefully analyzed so it can be understood by all audiences” (Pavlish and Pharris, 2012, p. xx). This was achieved during the final focus group in which the researchers met with the women to share identified patterns and themes that had been analyzed.

### **Transforming Insight into Action**

CBCAR is defined as “a relationship-based research process with the goal of social change and impactful action” (Pavlish and Pharris, 2012, p. 5). This study had great positive impact on the lives of this group of refugee women. The women organized themselves into a group they called the South Sudanese Women for Change Committee (SWCC), and are currently working on attaining a 501(c) 3 to become a non-profit organization. The women’s health seminar had immediate positive reactions, as 5 out of the 13 women in attendance at the first session on well-woman health obtained a mammogram for the first time. The SWCC has formed a partnership with Heart to Heart International in Kansas City. Two shipments of medical supplies will be sent to South Sudan to aid family members and

loved ones abroad. On World Health Day, Saturday April 7, 2012, the SWCC presented Heart to Heart with the new South Sudan flag at the Global Distribution Center. The SWCC is also planning a community health event with Heart to Heart spring 2012.

### **Reflecting on Evolving Pattern**

The final step of CBCAR involves evaluating actions and considering new questions (Pavlish and Pharris, 2012). In this process of dissemination, challenges with the process of conducting a CBCAR with Sudanese refugee women to address their health issues were examined. Challenges for both researchers and participants were identified in this study.

### **Challenges for researchers**

There were many challenges associated with this study that reflect a partnership of two completely different cultures. The first of which was an issue of collaboration. Researchers expected participants to take more responsibility for the project and initiative to organize themselves. Punctuality was an issue, as educational seminars sometimes did not get started until over an hour after the decided scheduled time. This was sometimes due to the more relaxed 'African culture', lack of communication among participants, and not reminding each other of the meetings, as well as limited transportation for participants. Not getting started on time pushed back researchers' schedules and limited the time allocated for focus group dialogue as the babysitter's schedule and church contract also needed to be respected.

One of the definitive features of CBCAR is equal involvement between the researchers and the community, which proved to be a complicated task. There was inconsistency in the number of participants each session due to competing events such as Southern Sudan Independence Day celebrations and a memorial service. Some of the women were unable to attend sessions because they were at home making food for the events. The interpreter and many women traveled back to Sudan for several weeks around this time, which delayed the group meetings. Constant efforts were made to engage the women to share responsibility for the group. Women were encouraged to identify topics and communicate with other members to remind them of group meeting dates and times. Lack of communication within any research study is a major concern that may have affected the outcomes of the study.

There were many obvious dialogue challenges, as participants did not speak the same language as researchers. For the language barrier, an interpreter was required to interpret English, Arabic, and Dinka. This alone required more time and increased the odds of participants' statements and opinions to be taken out of context or misunderstood by researchers. The women who did speak English had thick accents, and were hard to understand. Another challenge with the focus group dialogue was the matter of sharing subjects that would not normally be socially acceptable to discuss in the South Sudanese culture. For example, it was brought up in discussion that it is acceptable for a young Sudanese widow to move in with her brother-in-law, who will take over responsibilities of caring for the woman and her children. This topic was not discussed in depth, as an elder Sudanese woman said something in Dinka to the interpreter telling her to move to another subject.

Elder women kept younger women in line by enforcing cultural codes when discussing sensitive educational topics, such as reproductive health and sexually transmitted infections. This was also seen when an elder woman interjected during conversation about discrimination in America towards black Africans, advised the interpreter to change subjects. Traditionally, it is taboo for the women to admit to being depressed or overwhelmed with anxiety, which was noted in the women's stress seminar.

### **Challenges for participants**

One challenge with this partnership, from the perspective of the refugee women, was misunderstandings of what the group meetings would accomplish. Participants had different expectations of researchers. Several of the women believed that they would be trained to become a Certified Nurse Assistant (CNA) and thus acquire job skills as a result of participating in these sessions. One woman stated that she wanted the sessions "to be more like a training, so when we graduate from here we can have like license or certificate." Participants requested certificates at the last session, and received certificates of completion of the study, but not certification of clinical skills, as they had expected.

At the conclusion of the action planning session, several participants stayed to discuss their "frustration and disappointment" with the project. During this session, one woman stated her expectations of the researchers to "buy the medicine and go to help some people" in Sudan. She was dissatisfied with the project as she thought the project would raise money to fund their family and friends in Sudan. These misunderstandings may cause

distrust between the participants and researchers and lead to difficulty in future partnerships.

Another big challenge for the participants was the issue of gossiping. The CBCAR focus groups had to remain confidential despite being in a culture with a lot of gossip. Most refugees are isolated from the American society and must rely on each other for support. A participant shared how the Sudanese women “don’t tell all of the secret” because of “gossip going on...that’s why people keep things to themselves.” Another participant shared how Sudanese gossip is worse than American gossip. These cultural tones may have prevented the women from feeling comfortable to share information during the focus groups.

### **Discussion**

In summary, university researchers and South Sudanese refugee women were able to work together to identify health issues. Similar to the results of Schweitzer’s (2006) study, concerns about family still in Sudan, difficulties with seeking employment, and conflicts adjusting to new cultural values and beliefs outside of Sudanese tradition all posed challenges during the resettlement process for Sudanese refugees. Participants wanted to attain job skills from the seminars to help with employment. One of the graduate nursing students on the research team, who was also an immigrant to the United States, noted that refugees have a different outlook on adapting to American culture than immigrants. She explained that she chose to come to the United States, but refugees do not. This student speculated that refugees who are forced to live in the US might be “resistant to learn things” in the US because they have the expectation they will return to their homeland. This sense of temporariness may have affected the results of the study.

This study showed that developing a trusting partnership with the community is essential for CBCAR. In this study, similar to Pavlish’s study (2012), a refugee was used as an interpreter for the focus groups, which proved to be a positive link between researchers and participants. The theme of “hope for the future,” from Baird and Boyle’s ethnographic study (2011) also emerged from the CBCAR project. Participants were very focused on helping their family abroad, and as a result, were able to partner with Heart to Heart International to send medical supplies to South Sudan.

### **Implications for Nursing**

This study has many implications for nurses and other healthcare professionals. Refugees face many challenges with America's health system. As a nurse it is very important to practice with cultural competence and an open mind and to take the time to understand what the patient has experienced, because it makes a big difference not only in his/her care, but the way he/she experiences living in the United States.

### Conclusions

In conclusion, this CBCAR study demonstrated the importance of partnering with refugees to address their health issues. There were many challenges with this partnership for both the researchers and participants. The main challenges included misunderstandings, differing expectations, language barriers, and cultural differences. However, even with these multiple challenges, participants have taken initiative to transform insight into action when addressing health issues for themselves and their community.

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